

Statement on Decision-making in Cancer Care

As the number of cancer survivors in the United States nears 14 million, and as the “baby boomer” population ages, the demand for cancer care will grow. Additionally, the emergence of personalized medicine in oncology adds to the complexity of care planning by introducing exciting and individualized therapy options as well as a different set of risk and benefit calculations than previously required. While health care reform includes many important consumer protections, the ambiguity of the current economic environment and the future of health care policy could make the economic impact of a cancer diagnosis challenging for many patients.

Conversations about health care reform place a premium on improving the “value” of care, which is typically a measure of outcome (overall survival) and cost, often without regard to how patients define value. As discussions revolve around quality versus quantity of care, including the goal of improving the “value” of care, new strategies are changing the way cancer care is delivered and reimbursed by public and private payers. However, these efforts may have unintended consequences that negatively impact quality of life and health outcomes for patients.

Some examples of these strategies are:

- ***Clinical pathways***: These are tools used by health care teams in making treatment decisions. Most are evidence-based guidelines that many payers encourage care teams to follow in order to standardize treatment. These guidelines are often based on clinical trial endpoints instead of broader patient outcomes, thus the guidelines may not apply to all patients. Furthermore, clinical pathways may not reflect treatment impacts that are important to some patients when choosing among available treatments, such as neuropathy or other side effects that affect the patient experience. Since not all patients respond to a given treatment in the same way, there cannot be universal treatment approaches for all cancer patients.
- ***Step-edits or fail first***: These programs require a patient to “fail” (or see no disease improvement) on an ‘effective’ but less expensive treatment option before receiving an option that may be more costly. Given that patients have unique genetic profiles, comorbid conditions and other personalized considerations, these policies may cause delays in patients gaining access to the treatment(s) that might be the better matched therapies for the individual patient. While some payers offer medical necessity exceptions from these policies, such exceptions may be very difficult and time-consuming to obtain, delaying access to time-sensitive therapy.

- **Specialty tiers for prescription drugs:** Certain prescription drugs are placed on “specialty tiers,” resulting in larger out-of-pocket costs to the patient. Specialty tiers often require the patient to pay an amount based upon a percentage of the cost of drug rather than a fixed dollar amount (i.e., 20% of the drug cost versus a \$10 co-payment). As a result, specialty tiers can limit access to lifesaving medications by making them too expensive for patients. One study has shown that patients with prescription co-pays of \$500 or higher are four times more likely to abandon treatment than those with lower co-pays.¹
- **Bundled payments:** These are programs that reimburse care teams for an entire health care episode and allow providers to share in any cost-savings achieved through providing more efficient care. The evidence upon which the shared savings guidelines are established, as well as the payer and provider’s incentive agreements are often not transparent to the patient and may result in patients receiving less expensive and/or inferior treatment in exchange for increased profits to bundled payment beneficiaries.

Data collected through the Cancer Support Community’s (CSC) Cancer Experience Registry, a database and community of over 7,700 people with all types of cancer, indicate that quality of life issues and attention to individual preferences and needs are key factors in patients’ definition of value.

When asked to define value in the context of their cancer experience, registrant responses include:

- “Value is most meaningful when it is applied to my individual life, and not to an algorithm or statistical fact”
- “Being informed, empowered and part of the decision-making”
- “Being treated as an individual not a diagnosis”
- “Balancing quality of life with effective treatment”
- “Any actions that supported my personal approach to my cancer adventure”

¹Streeter SB, Schwartzberg L, Husain N, et al. (2011) Patient and plan characteristics affecting abandonment of oral oncolytic preparations. *J Oncol Pract* 7(suppl 3S):46s–51s.

CSC recognizes the above strategies as efforts to control the unsustainable and rising cost of cancer care while maintaining quality. However, policies that aim to improve the value of health care must involve the input and alignment of all stakeholders – patients, providers and payers. With regard to the above strategies, CSC’s position is that the following tenets must be incorporated in any and all health care decision-making and in broader policy discussions:

1. Since patients have differing responses to treatments and personalized medicine is offering more targeted options, care plans must be customized for and with the individual cancer patient at the center of the discussion. It is critical that providers have autonomy to exercise discretion in treatment recommendations using clinical evidence as one fundamental tool, and that the patient’s definition of ‘value’ is an integral part of the decision-making process. At the same time, affordability and other access limitations must be minimized in support of patient adherence to the best care plan for him/her. Decisions should be based on evidence specific to the patient’s individual clinical and biological profile, input from the patient regarding his or her goals of therapy and full disclosure and agreement about the cost implications.
2. There should be total and accessible transparency in both the data used for decisions and also the incentive structures offered to the health care team and/or the patient for choosing a specific treatment plan.
3. As a fundamental element of comprehensive, quality cancer care, psychosocial screening, support and care should be a required and reimbursed service. The evidence regarding psychosocial intervention on improved patient outcomes and decreased overall costs support total integration into the overall cancer care continuum.

CSC strongly supports access to patient-centered, high quality, comprehensive cancer care for all people with cancer. Public policies and health care delivery models should support the patient-physician dialogue and shared decision-making to arrive at evidence-based care plans that incorporate patients’ values and preferences. Patients should have access to all cancer treatments deemed appropriate and necessary following an informed, evidence-based dialogue between the physician and the patient that incorporates consideration of the patient’s definition of value and the impact of the care plan on the overall patient experience.

About the Cancer Support Community

The mission of the Cancer Support Community is to ensure that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. In 2009, The Wellness Community and Gilda's Club joined forces to become the Cancer Support Community (CSC). The combined organization, with more than 50 years of collective experience, provides the highest quality social and emotional support for people impacted by cancer through a network of over 50 licensed affiliates, more than 100 satellite locations, and a vibrant online community, touching more than one million people each year.

Backed by evidence that the best cancer care includes social and emotional support, CSC offers these services free of charge to men, women, and children with any type or stage of cancer, and to their loved ones. As the largest, professionally led nonprofit network of cancer support worldwide, CSC delivers a comprehensive menu of personalized and essential services including support groups, educational workshops, exercise, art and nutrition classes, and social activities for the entire family. In 2012, CSC delivered more than \$40 million in free services to patients and families.

In 2009 CSC opened its *Research and Training Institute* – the first independent Institute in the United States dedicated to psychosocial, behavioral and survivorship research and training in cancer. In 2013, CSC launched the *Cancer Policy Institute* to ensure patient-centered, comprehensive, quality cancer care through three strategic pillars: **Access** to care for all patients; **Quality** as a central theme and; **Research** as a critical priority to advance overall care.

CSC is advancing the innovations that are becoming the standard in complete cancer care.

For more information, visit CancerSupportCommunity.org